



December 20, 2018

The Honorable Nicholas G. Garaufis
United States District Judge, Eastern District of New York
United States Courthouse
Room 1426 S
225 Cadman Plaza East
Brooklyn, NY 11201

Dear Judge Garaufis:

We are writing on behalf of the the National Alliance on Mental Illness (NAMI), NAMI-New York City, and NAMI-New York State to express our views about the *ProPublica* and *Frontline* investigation published in the New York Times on December 6, 2018 entitled [Living Apart, Coming Undone](#). NAMI is the nation's largest grassroots organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI operates at federal, state and local levels and this letter is being submitted jointly by our three organizations, who will collectively be referenced as "NAMI" throughout this letter.

The *ProPublica* and *Frontline* investigation documented that while many people who have moved out of adult homes into supported housing pursuant to the settlement in 2013 have done well, a number of people have not done well. At least thirty-two people have died, and others are living in substandard conditions without adequate supports. The story further revealed that the state departments responsible for implementing and overseeing the settlement did not have systems in place for tracking the status and progress of individuals transitioning from adult homes to supported housing until very recently.

The original [Broken Homes](#) series published in *The New York Times* in 2002 revealed horrific conditions and abuses of residents in adult homes. The series further revealed that many of the residents of these adult homes had the capacity, with appropriate services and supports, to live in more integrated supported housing settings in the community. Thus, NAMI joined other mental health and disability advocacy organizations in submitting an *amicus curiae* brief urging the U.S. Court of Appeals for the Second Circuit to affirm your landmark decision finding that the class members had a right under the Americans with Disabilities Act to live in the most integrated setting appropriate to their needs and wishes.

NAMI recognizes that many people have successfully transitioned into supported housing and we also recognize that these stories may not get told. We appreciate the work that has been done under the court's direction and remain committed to the goals of the adult home settlement. We believe that many of the class members are capable, with appropriate services and supports, of living in less restrictive settings than long-term placements in state hospitals or adult homes.

However, the revelations in the *ProPublica/Frontline* investigation raise serious questions about whether all people being transferred out of adult homes are in fact receiving appropriate levels of services and supports, including adequate assessments prior to leaving adult homes. The investigation also reveals that there have been significant problems with monitoring the well-being of individuals who have been transferred from adult homes into the community.

We support your call for certain improvements at the status hearing of December 6th, including an independent report to assess the effectiveness of the state's incident reporting system, an examination by the state of the Adult Home Plus coordination program, and the development of a program to help people learn and practice basic life skills before transitioning into supported housing. Additionally, NAMI believes there needs to be more emphasis placed in conducting thorough individualized assessments performed by qualified licensed clinicians who know the strengths and limitations of the system before class members transfer to less restrictive settings to ensure that appropriate wrap around services and supports are in place with funding.

We also believe that there must be recognition that some individuals leaving adult care homes may require twenty-four hour, seven day a week care and support in supervised settings. These services need not be provided in large institutional facilities but can be provided in smaller settings, such as group homes and other residences. Since many of the former adult home residents have lived outside of the mainstream of society for many years, it is unrealistic to expect that all class members can live safely in unsupervised scattered-site apartments, even if that is their stated preference. The capacity of some individuals to make informed choices about housing may also be impaired in some cases due to severe mental health symptoms. Thus, while it is very important to honor the stated preferences of individual class members whenever possible, when the need for heightened levels of needed care make the choice of scattered site housing unsafe, alternative options should be considered, such as group homes or apartments with 24/7 supports.

Additionally, NAMI urges that there be greater recognition and engagement of families of individuals transitioning out of adult homes in all aspects of the process. Families of adults who live with mental illness are crucial to caregiving, support and recovery. Proactive efforts to involve and support families should therefore be part of the transition and care process moving forward. Families and caregivers should also be provided with information necessary to serve effectively in these roles.

A fully funded workforce is necessary for effective implementation of the adult home settlement. Unfortunately, New York State has continually failed to make necessary investments in recruiting and retaining qualified mental health professionals. We therefore urge that all mental health professionals engaged with adult home residents, including residential counselors, care managers and peer support specialists, be paid living wages and cost of living increases tied to the consumer price index (CPI) on an annual basis.

Finally, we believe the state must implement a far more transparent system for reporting information to stakeholders about the status of settlement implementation. This must include detailed information about deaths and other serious adverse incidents. We are particularly concerned that the state has refused to divulge information about the results of investigations into the deaths of individuals. While we respect the importance of confidentiality, information about deaths and serious adverse incidents can be revealed without revealing individually identifiable information or violating the rights of those directly impacted.

Judge Garaufis, NAMI greatly appreciates your long-term involvement in this case and your dedication to ensuring that the transition of adult home residents to community settings occur properly and safely. We recognize that implementation of a comprehensive settlement agreement affecting individuals with complex needs is very difficult. It is important that adjustments and modifications are made when problems of the magnitude described in the *ProPublica/Frontline* investigation are revealed and we are confident that these changes and improvements will occur under your stewardship. As the largest organization representing people with mental illness and their families, we request that NAMI be included among those who receive reports and that our input into the process, along with other stakeholders, be sought as implementation of this settlement continues.

Respectfully,



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